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Appendix

Introduction

Overview of Disabilities Policy in Maryland

Disabilities and needed long-term support services can be organized by population on (1) the basis of the age of the disabled person e.g. school age, working age, retirement age, (2) the basis of type of disability e.g. developmental disabilities, adult cognitive disabilities, deafness, blindness, mental health, paralysis, or (3) the basis of type of service e.g. special education, paratransit, supported employment, assistive technologies, housing, home aides. Maryland has organized disability services on the basis of all of these categories. As a result, responsibility for disabilities services is diffused among eight cabinet level departments, 15 administrative units and 99 separate programs (see 2007 State Disabilities Plan). This dispersion of responsibility, however well-intended or logical in some respects, results in major problems of transparency, accountability, efficiency, and coordination in disabilities policy.

As an example, there is little transparency on issues as basic as how many persons receive or are eligible for services because different programs use different eligibility criteria, because different programs do not compare participants to those of other programs, or coordinate efforts. We do know that very large numbers of persons are potential users of state services.

The Census Bureau reported that in 2000, 854,345 persons or 17.6% of all Marylanders had a disability. Of that number, 96,501 or 8.1% of all persons 5-20 years old had a disability; 529,949 or 17.2% of all Marylanders 20-64 had a disability and 227,895 or 39.8% of Marylanders age 65 or older had a disability. The Maryland Department of Planning estimated that in 2005, 911,059 or 17.8% of all Marylanders over 5 years of age had a disability, an increase of over 60,000 persons in 5 years. The largest group of persons with disabilities is in the age group of 20-65. Thus, the potential pool of users of services for persons with disabilities is large and growing.

Transparency is also a problem with respect to funding. The Department of Disabilities has analyzed the 2007 State budget and determined that the total State appropriation for primary disabilities programs is \$4,337,704,920 or 14.8% of the entire State budget. This number however, does not appear in a consolidated budget and no single person or agency is responsible for this amount of money. We would note that 14.8% of the State's budget is being spent on a group which constitutes 17.8% of the State's population.

Accountability is a serious issue for several reasons. Each of the eight Departments is free to make budget and policy decisions on disabilities without regard to decisions made by the other Departments. Furthermore, disabilities is a significant policy area for DHMH, DHR, MDoA, and MSDE, but only a secondary or tertiary concern for other departments. Issues of vital concern to persons with disabilities often are stepchildren of various departments which do not dedicate sufficient attention or resources to the issue. As a result, to a surprising extent policy develops as a result of litigation brought by frustrated members of the disabilities community.

The division of authority also causes problems with coordination of policy at the governmental level and of services at the personal level. At the personal level, persons with disabilities and their families face daunting challenges in assembling from a multitude of programs, the appropriate mix of support services. A number of our recommendations relate to secure coordination. At the policy level, there is little real coordination among the departments and policy is made in a disjointed manner. In the final analysis, the only person who has authority over all eight Departments, 15 administrative units, 99 programs and all of the persons with disabilities in the State is the Governor himself. Accordingly, one of the key recommendations we make will be for the appointment of personnel in the Governor's office to coordinate effort at the Departmental level.

Maryland is 35th in the nation in terms of the degree to which its Medicaid budget is apportioned toward community-based supports versus institutional supports. To reverse this direction and to make Maryland one

of the states that is leading the way in (1) implementing the Olmstead case requirements to have a plan and to work toward serving people in the least restrictive environment possible and (2) shifting the balance of long-term supports toward less expensive and more desirable community-based services, it is essential to overcome fragmentation and territorialism among state agencies and programs. This paper will recommend the creation of two staff positions reporting directly to the Governor with the responsibility and authority to facilitate collaboration and change within the long-term support and disabilities sector of state government.

Maryland needs to shift from providing services to people with disabilities including seniors from primarily in institutions to primarily in the community (long term services reform) in an accountable way both because Medicaid expenses must be controlled and because most people prefer to remain in their own homes with supportive long-term services. To create this shift, leadership, direction, and vision in Long Term Services planning is needed from the Governor's office across State Departments including the Departments of Health and Mental Hygiene, Aging, Human Resources, Housing, Transportation and Disabilities.

This leadership requires two new positions of Long Term Services Reform Director and Long Term Care Reform Manager in the Governor's Office charged with responsibility for: bringing the State Departments together that provide and finance long term services, providing the Departments with the Governor's vision for long term services, assuring Departmental buy-in, developing an integrated cross-Departmental plan with the Secretaries to implement the plan and evaluating success using quantitative measurements. One function of this leadership will be to minimize territorial protection.

The Governor's leadership includes creating an interdepartmental long term services reform action group at the Secretarial level with an implementation team composed of the Deputy Secretaries from each Department. The LTCR Director is the Director of the interdepartmental long term services reform group with authority to resolve interdepartmental issues on behalf of the Governor.

The Governor's leadership is also exercised by appointing Secretaries who understand the long term services reform agenda and are capable of providing Departmental leadership directed toward achieving the needed change in the State's system of services even though their staff and bureaucracies may be enmeshed in current operational and philosophical structures and who are committed to working cooperatively with the Secretaries of other Departments. Such Secretaries will care about all populations who need long term services to live in the community, not only seniors or only people with specific disabilities.

The Department of Disabilities was created in 2004 to coordinate and analyze policy on a comprehensive basis. One product of the Department is the Disabilities Plan. The work group also recommends that the recommendations of this Transition Workgroup be incorporated into the 2007 Disabilities Plan and that the Plan be implemented.

Charge to the Disabilities Transition Workgroup:

The Transition Work Group has been charged with examining public policy in the area of disabilities to make recommendations to the Governor and his administration on disabilities policy. The Transition Work Group has 42 members, each of whom has actively participated in the preparation of this report. The members of the Work Group include persons with disabilities or family members, leaders of advocacy organizations, professionals in the field, and other activists.

The Work Group has been subdivided into four subcommittees dealing with particular areas of concern, community supports, Olmstead compliance/institutions, education including early childhood, special education and vocational rehabilitation and Department of Disabilities/Office of Deaf and Hard of Hearing. Each subcommittee worked diligently to conduct research, including interviews with State Employees, and

to formulate recommendations. The recommendations which are in this report represent a consensus of the work group. However, we would note that not every individual agrees with every recommendation. Additionally, even if an individual agrees with the recommendation, it cannot be assumed that the organizations which that person belongs to agree with the recommendation.

Each recommendation has been given a numbered code to the right of the title of the recommendation. The first digit of the code indicates whether the recommendation is of the highest priority (1) or priority (2). The second digit indicates whether the proposal is easy or inexpensive (1), whether it is more challenging and/or expensive (2) or difficult or very expensive (3). A recommendation of 1.1 indicates that the recommendation would be high priority and relatively easy or inexpensive to accomplish. A 2.2 would indicate that the recommendation is a priority, but more difficult or expensive.

Olmstead/Institutions

2.1. A. Develop an Olmstead Plan

Rating: 1.2

(a) Issue:

The United States Supreme Court in the landmark *Olmstead*¹ decision affirmed the right to receive public benefits in the most integrated setting appropriate and laid out clear parameters for states to follow. In *Olmstead*, the Court ruled that the inappropriate institutionalization of qualified individuals with disabilities is discrimination under the ADA because institutionalization segregates individuals with disabilities from everyday life activities and diminishes individual opportunity. The Court made clear that under certain circumstances, states and public entities are required to provide community-based services to people with disabilities and to make reasonable modifications in policies, practices or procedures when modifications are necessary to avoid discrimination on the basis of disability. The Court also suggested that a state could establish compliance with the ADA's reasonable modification requirement if it demonstrates that it has: a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by the state's endeavors to keep institutions fully populated.

The U. S. Departments of Justice and Health and Human Services have called upon states to swiftly implement the *Olmstead* decision and have collaborated with other federal agencies to assist states through coordinated technical assistance. According to the National Conference of State Legislatures, since the *Olmstead* decision, at least 44 states and territories have engaged in planning efforts to increase community options for people with disabilities. Although Maryland initiated Olmstead planning activities in 2001 and 2002, implementation has not occurred.

(b) Recommendation:

1. Implement a comprehensive, effectively working plan to ensure that all people with disabilities are provided services in the most integrated setting. This plan should provide specific action steps and timelines for closing and/or downsizing institutions and to prevent future unnecessary institutionalization. To make this plan effective the following steps should be implemented.
 - a. The Governor should appoint a planning group to develop the plan that includes people with disabilities, family members, advocates and other stakeholders who bring expertise to the expansion of community services.
 - b. The planning group should receive administrative support and information from Maryland agencies that include: DOD, Health and Human Services, Education, Labor, Transportation and Aging.
 - c. The Governor should appoint a full-time management level staff member who reports directly to the Director of DHMH to facilitate the planning process and report on plan implementation.

¹ *Olmstead v. L.C.*, 119 S. Ct.2176 (1999)

- d. The plan should include data on all people with disabilities who are currently living in publicly operated and publicly funded institutions in Maryland. Institutions are defined as ICF/MR facilities, nursing facilities, psychiatric hospitals, and residential programs serving more than seven individuals with disabilities.
- e. The plan should also include a process for conducting, by qualified and independent professionals, setting-neutral assessments for all people with disabilities who are currently institutionalized and those who are at risk of institutionalization.
- f. The plan should include provisions for notifying people with disabilities of their right to receive services in the most integrated setting.
- g. The plan should aggressively utilize grant and waiver funds made available through the recent award to Maryland of money-follows-the-person grant by the US Department of Health and Human Services and provide for legislation to fund the state's share of money-follows-the-person initiatives.
- h. The plan should be completed in time for the preparation of the next Governor's budget.

(c) Analysis/Background:

Research, public practice and public policy all favor community living for almost every person with a disability. Already, ten states have no one with developmental disabilities in large, state operated institutions. Some people with serious and persistent mental illness are well served in intensive residential institutions and some people with Alzheimer's and advanced dementia need secure 24/7 support. Maryland has experience in providing community-based support, through an extensive network of primarily private not for profit organizations. Those organizations have the capacity to expand with the addition of state resources now being utilized to maintain unneeded institutions. In addition, there is, as Maryland's population is aging and as people with significant disabilities are, for the first time in history, living to old age, a substantial waiting list of qualified individuals in need of care. As these individuals have lived with families for 20, 30, 40 and even 50 years in Maryland's communities, institutionalization is neither a logical or necessary option. Maryland has the opportunity to, in a planned and well managed fashion, take national leadership in the provision of competent and fiscally responsible community-based care for all but a small percentage of its residents with disabilities.

Olmstead/Institutions

2.1.B Transition and Close State Facilities

Rating: 1.3

(a) Issue:

For over three decades, the developmental and psychiatric disabilities fields have moved from institutional, medical models to home and community based support, founded on the principles of normalization, person-centered planning and self-determination. Nevertheless, despite numerous studies, reports and recommendations to downsize state residential centers (SRCs) and/or close them, there has been no significant movement or progress over the last seven years in affording people with developmental disabilities their right to live in the least restrictive setting in Maryland.

Similarly, Maryland's institutional bias for people with psychiatric disabilities is fiscally and morally untenable. Maryland ranks number one in the country for the most state-operated hospitals per capita and spends 33 percent of its mental health budget to serve four percent of eligible participants in the public mental health system in segregated settings. Hundreds of individuals continue to languish needlessly in institutions, causing mental, physical and spiritual deterioration and depriving individuals and society of the benefits of full inclusion.

(b) Recommendations:

- The state should take the opportunity to provide institutionalized persons with disabilities their right to the most integrated setting, appropriate to their needs. The state's limited resources should be used for the transition and closure of Rosewood and Brandenburg State Residential Centers and Spring Grove Hospital Center, rather than pouring money into futile attempts to renovate aging buildings or

fix historic problems that serve to perpetuate these out-dated models of services to persons with disabilities. To this end, the State should:

- Implement a Transition Plan to transition all Rosewood State Residential Center, Brandenburg Center, and Spring Grove Hospital Center residents to appropriate quality, safe, community-based and less restrictive programs and close these three centers over the next two years. The plan should include: (1) immediate review of the health and safety of all residents, including those committed by the courts; (2) creation of a task force to guide the transition and closure of the three centers, establish collaboration among stakeholders to deal with systemic issues, and examine alternative uses for the properties; (3) service models that comply with best practices for evaluating and supporting individuals with psychiatric, cognitive and developmental disabilities with court-ordered placements in more appropriate treatment settings; (4) assistance to permanent state employees in these centers in filling vacant positions within DHMH or other State agencies, including retraining if necessary and desired.
- Implement a Statewide SRC and Psychiatric Hospital Downsizing Plan that includes options needed for community respite care and rural health and psychiatric networks to prevent institutional placements. Maryland must develop the home and community supports needed rather than in effect forcing families to accept institutional care due to lack of community services. No individual with disabilities or family should be forced to accept institutional care. There is no “choice” when families can only get respite care in an institution, rather than in their home or community.
- Provide outreach and support to individuals with disabilities in SRCs and psychiatric facilities about their rights to receive services in the most integrated setting. Such outreach and support should be provided by individuals with disabilities through self-advocacy leadership groups.
- Stop new admissions to SRCs and instead provide appropriate supports in the community. Require state psychiatric hospitals to transition individuals to appropriate community supports and services no later than 6 months following admission.
- Provide matching funds in the FY 2008 State Budget to transition 50 people out of SRCs to appropriate community supports. Maryland was awarded a federal CMS grant through the Money Follows the Person Rebalancing Initiative. The grant provides a higher match to transition 50 people per year for five years from SRCs to community supports.

(c) Background/Analysis:

Maryland operates four State Residential Centers (SRCs) housing 400 individuals with developmental disabilities and has ten psychiatric facilities at which 3,422 individuals are admitted annually. State law (Health-General Article, section 7-904) requires an Individual Written Plan of Habilitation for each individual residing at an SRC. Ninety percent of the individuals reviewed pursuant to this statute have a finding from the independent resource coordinator that community residential services are the most integrated setting appropriate to meet their needs.

Rosewood Center in Baltimore County houses 200 people, a subset of whom have court-ordered placements. The Office of Health Care Quality found that individuals at Rosewood Center were in immediate jeopardy of harm and significant deficiencies in the services provided in violation of federal and state regulations.

The Department of Health and Mental Hygiene’s Report On *Closure of a Residential Facility for People with Developmental Disabilities* (2004) determined that if a State residential center were to be closed, the Department would recommend the Rosewood Center; that closure of Rosewood Center would yield the most

beneficial results in terms of savings to the State, and that closure of Rosewood would generate long-term savings that benefits individuals with developmental disabilities living in the community who are waiting for needed community services through the Waiting List Equity Fund and the Community Services Trust Fund.

Brandenburg Center in Western Maryland serves 22 individuals with developmental disabilities on the grounds of the Finan Center, a state psychiatric facility. In 2004, DHMH reported that community based services would save an average of \$28,239 per person compared to facility based care.

Spring Grove Hospital Center has 439 beds. Approximately two-thirds of these beds are allotted for non-acute, long-term care. The average annual cost to serve a long-term patient is \$180,000. The cost of community care, by contrast, ranges from \$14,000 to \$35,000. Moreover, unlike community services, institutional care is not eligible for the 50 percent federal match under Medicaid for patients who are between the ages of 18 and 64. In addition, not only is the cost of serving people in the community far less, several reports released by DHMH in the past few years conclude that the State would realize huge savings by diverting ever-increasing resources away from maintaining this aging facility that is mostly in poor condition and in chronic need of repairs.

Approximately 50 percent of all state-operated psychiatric beds are for court-ordered individuals. Of the court-ordered individuals (also referred to as “forensic”), only a small number may actually require a locked, secure environment. The majority of individuals labeled “forensic” are placed in state institutions for minor or long-ago offenses and deserve the opportunity to live in a less restrictive setting.

Fiscal Implications: The DHMH 2004 Report listed the costs associated with the first year of closure of Rosewood Center at \$7,464,000, with long-term net savings ultimately realized. The Department of Legislative Services (2004) projected general fund savings of approximately \$11.8 Million over five years by moving residents from Rosewood Center to the community. In 2003, the Department of Legislative Services estimated that the long term operating savings to be gained from closing an older facility such as Spring Grove could be as much as \$10 million.²

Olmstead/Institutions

2.2. Personnel Enhancement

Rating: 1.2

(a) Issue:

In order to implement the recommendations of this workgroup, we recommend that the State enhance its staffing with respect to certain key functions as follows:

(b) Recommendation:

The Secretary of DHMH shall appoint a Special Assistant for Olmstead Implementation and Oversight. This individual shall report directly to the Secretary.

The Secretary shall ensure that the Office of Health Care Quality (OHCQ) is provided with incremental staffing capacity to enable it to effectively monitor all State operated facilities as well as community services. Current staffing resource for OHCQ surveyors needs can be found in the *OHCQ Report to the General Assembly Pursuant to Health-General Article §19-308(b)(7) and April 2006 Joint Chairmen’s Report – Operating Budget October 2006* or at the following link to the PHCQ website:

<http://www.dhmh.state.md.us/ohcq/reports/jcr2007.pdf>

² The Maryland Coalition of Advocates for the Retarded (MCAR) disagrees with this recommendation on the grounds that; (1) closure of facilities would force individuals out of these facilities against their will and (2) that Olmstead did not mandate the closure of State facilities. MCAR supports improvements to Rosewood and Brandenburg rather than closure, elimination of waiting lists for community supports, the development of community resource centers at State residential facilities, and the maintenance of a State institutional resource for persons with disabilities. This recommendation was the subject of considerable debate, and the consensus of the balance of the committee, and of the Co-Chairs of the Workgroup was to adopt recommendation 2.1.B. of this report on the grounds stated.

(c) Analysis/Background:

In order to successfully comply with its obligations under Olmstead, it is important that the Secretary designate a high level position to coordinate DHMH compliance efforts and to collaborate with the Secretary of DOD. Concurrent with such coordination and collaboration, there is the need for enhanced monitoring by OHCQ of both State facilities and community services.

The increase in staffing capacity for OHCQ should include: (1) an incremental increase over the next four years to assure sufficient staff to handle existing work load, to include an increase in oversight responsibilities for the State psychiatric hospitals; and (2) a proportional increase in staffing as any facility is downsized or closed to assure that OHCQ can effectively monitor the quality of community services.

Olmstead/Institutions

2.3. Options Counseling for Nursing Facility Residents

Rating: 1.1

(a) Issue: People living in nursing facilities need information about community living options and do not necessarily receive it in a meaningful way.

(b) Recommendation: The State (DHMH) should contract with independent advocacy organizations, including the consumer controlled and directed Centers for Independent Living to provide Options Counseling to nursing facility residents.

(c) Analysis/Background:

Current options counseling is provided by nurses under contract to the State. However, the nurses are not expert in community based services and, thus, limited in their ability to explain the various services and resources that are available in the community and how to access them. Options counseling should be provided by the experts, including networks of consumer controlled and directed independent advocacy organizations that use a peer mentoring approach.

Such independent advocacy organizations are based in local communities, well informed about local and state programs and services for people with disabilities, have a strong commitment to creating successful employment for people with disabilities and will likely train and support individuals who formerly resided in nursing facilities to participate in delivering the options counseling service. Learning about community living options from a peer who has transitioned successfully from a nursing facility to community living is meaningful and motivational for individuals who typically are unaware of the community services, supports and resources available to them.

Olmstead/Institutions

2.4. Human Rights

Rating: 1.1

(a) Issue:

Persons with disabilities continue to face discrimination in Maryland. Discrimination against any person on the basis of disability is a violation of their civil rights, and inherent dignity and worth. While there are serious risk of injury and death due to unsafe conditions for people with disabilities, this is proportionally a much greater issue for those in institutional setting than in the community. The use of restraint and seclusion, and medical neglect continues within the facilities. Persons with disabilities are also routinely denied person-centered treatment and self-determination.

(b) Recommendation:

1. **Within the first 100 days in office, the Governor should by Executive Order issue a policy outlining zero tolerance of acts of intentional abuse, neglect and exploitation of persons with**

disabilities by an employee of the state, agent or provider in any and all settings. Elements of the Order should include, at a minimum:

- Developing the capacity to continuously track, investigate, remedy and punish such acts in a fair, consistent, and confidential but publicly transparent and timely manner;
- Analyzing such acts to identify possible trends and improved means for detecting and preventing similar acts from recurring in the future, and continuously assessing, incorporating and improving upon best practices in other states and jurisdictions;
- Implementing training and other supports aimed at equipping individuals with disabilities, paraprofessionals, family members and others with the knowledge, tools and supports to avoid such acts or report them should they occur;
- Regular reporting--at least two times per year--to the Governor, Legislature and public, upon progress in achieving the goals of the Zero Tolerance Policy.

2. The Governor should also propose or support legislation that strengthens current law and is designed to (1) end the use of restraint and seclusion, (2) protect individuals with disabilities from abuse and neglect, and (3) promote dignity, independence and recovery. Specific provisions should include, at a minimum:

- The right to be free from physical, mechanical and/or chemical restraint and seclusion absent an emergency safety situation in which the individual's unanticipated behavior places the individual or others at serious threat of violence or injury;
- Requirements for staff training on the use of alternatives to restraint and seclusion;
- The right to a self-determined plan of activities that help to soothe the individual in times of emotional crisis;
- The right to be free from any physical restraint or hold that: (a) places the individual face down with pressure applied to the back, (b) obstructs the airways of the individual or impairs the individual's ability to breathe, (c) obstructs a staff member's view of the individual's face, or (d) restricts the individual's ability to communicate;
- The right to prompt medical care and treatment, including emergency medical care;
- The right to a safe environment that is free from physical, mental and sexual abuse and harassment;
- The right to dignity, independence to the fullest extent possible, and to recovery, including (a) access to a toilet at any time; (b) regular physical exercise, recreational opportunities, and to go outdoors daily; (c) age-appropriate, clean personal clothing; (d) nutritious, appetizing food; (e) educational and therapeutic programs; (f) religious freedom and practice; (g) regular social interaction and participation in community activities; (h) adaptive devices such as eyeglasses, hearing aids, dentures, walkers, wheelchairs and communication devices.
- The right to a comprehensive assessment to identify an individual's abilities, needs and preferences and to develop an individualized treatment and discharge plan that enables the individual to successfully transition into the community.
- The right to have complaints investigated by an independent entity in a timely, thorough and fair manner; to have appropriate remedial action taken; and to have enumerated rights enforced in a court of law.

(c) Analysis/Background:

Existing laws regarding the use of restraint and seclusion violate federal regulations pertaining to psychiatric facilities and do not reflect best practices with respect to individuals with psychiatric and/or developmental disabilities. In addition, statutory rights for persons with developmental disabilities differ from those granted

to persons with psychiatric disabilities. Rights for all persons with disabilities should be uniform and expanded. Furthermore, ongoing violations, such as those at Rosewood State Residential Center recently uncovered by the Office of Health Care Quality, demonstrate that current laws (1) are not sufficient to protect individuals; (2) that staff are either unaware of basic rights or are not held accountable for violations of such rights; and (3) that a more vigorous system for investigating and remediation of violations is urgently needed.

Olmstead/Institutions

2.5. Assessment and Transition Planning

Rating: 1.1

(a) Issue: A comprehensive assessment and planning effort is needed in Maryland to foster the integration of individuals with disabilities into community life, provide resources to operate community services to support individuals with disabilities in the community, and reduce/eliminate reliance on institutions (large congregate facilities).

(b) Recommendation:

Every person with a disability currently residing in an institutional setting, or at imminent risk of being admitted to an institutional setting, shall receive a comprehensive, individualized needs assessment to determine the services and supports that would result in successful community transition. Nothing, including the nature or severity of an individual's disability, will be a factor in excluding a person from the assessment and transition planning processes as necessary or appropriate.

Assessments shall be conducted on a periodic basis. Individuals residing in institutional settings shall have the right to request an assessment at any time. Individuals residing in the community who believe themselves at risk of institutionalization shall also have the right to request an assessment.

Trained, experienced, independent assessors with competence in the comprehensive assessment and transition planning processes shall conduct all assessments.

Although court-committed individuals will be included in the assessment process, the nature of the criminal charges for some individuals may require the use of different assessment tools and transition planning by professionals with expertise in the forensic population. It is critical to recognize that there is significant variation in the circumstances under which individuals have been court-committed, and that many, in fact, have not been involved in crimes of violence. The Department will explore national best practices so court-committed individuals are not unnecessarily denied community transition.

In light of the different situations and needs of people with progressively deteriorating cognitive impairments that develop later in life such as Alzheimer's disease and related dementias, these recommendations should not necessarily be construed to pertain to these populations. However, there is a need to develop more dementia-capable home and community-based services and caregiver supports to help families care for their loved ones, and for the State to make those services accessible for people with Alzheimer's disease and related dementias.

The assessment process will, at a minimum, do the following:

- Collect information about the person's needs and choices regarding living arrangements, services and supports, including with whom the person would prefer to live and how s/he would like to spend time;

- Specify the community living arrangement, services and supports that would enable the individual to transition and live successfully in a more integrated setting, including those supports needed to promote the individual's community inclusion, independence, growth, health and well being;
- Identify the most integrated setting appropriate for the person considering his/her preference and needs, and determine eligibility for home and community-based services without regard to current availability of services;
- Determine what barriers, if any, currently exist preventing the individual's prompt transition to the most integrated setting, including the community living arrangements and/or ancillary services and support resources that need to be developed to meet identified service needs and choices of the individual.
- Provide complete, understandable information to the individual about the wide array of possible community living arrangements, services and supports;

Aggregate data shall be collected on all identified barriers to providing services to individuals in the most integrated setting. Data shall include types and features of living arrangements, services and supports currently offered but for which there is insufficient capacity, and services and supports not currently offered in the State that could be developed to meet people's needs.

Individualized transition plans shall be created for all individuals. Plans shall identify the services, such as overnight visits, for successful transition to community living. Peer advocates shall be made available, upon request, to persons with disabilities who will be transitioning out of institutions.

Prior to implementing the assessment process, DHMH officials shall meet with self-advocate organizations to develop best practice assessment and planning tools that will then be utilized in conducting the needs assessments and transition plans. Progress reports shall be made available to the public on a quarterly basis, specifying any barriers identified that prevent placement of individuals in the most integrated setting.

(c) Analysis/Background: The Subcommittee recognizes that Maryland must move beyond the outmoded institutional models of the past, and promote integration and inclusion of people with disabilities into our communities. It is imperative for the State to prevent or minimize the institutionalization of people with disabilities and their dislocation from family, friends and community. Therefore, Maryland must undertake a comprehensive assessment and transition planning process as fundamental to meeting the needs and choices of each person, regardless of age or degree of disability, and to promoting his or her integration into the mainstream of the community.

The appropriate array of services and supports that must be provided to people with disabilities shall be determined through an individual planning process which includes a comprehensive assessment of individual strengths, needs and preferences. For those individuals who reside in institutions, the assessment results shall be used to develop an individualized transition plan that will result in timely movement to the most integrated community setting that will meet the individual's needs. Plans must include goals that maximize opportunities and teach skills needed for each person to develop relationships, be part of community life, increase control over his or her life and acquire increasingly positive roles in the community.

Community Supports

3.1. Reducing Waiting Lists for Community Long Term Care Supports by Implementing Specific Waiver Expansions

Rating: 1.3

(a) Issue: The need for community long term care supports for younger adults and children is significant, as evidenced by the waiting lists for the Living at Home and the Traumatic Brain Injury Waivers, as well as the Model Waiver for children with complex medical needs and disabilities.

(b) Recommendation:

- Expand availability of the LAH program by increasing slots by 100 per year.
- Maintain comprehensive care coordination for the LAH and Model Waiver populations, independent of any managed LTC program to optimize cost efficiencies, quality and choice.
- Carve out younger adult populations from any managed LTC approach (such as Community Choice or the CCO pilot).
- Expand the existing Model Waiver program by 50 slots this year.
- Expand the existing TBI waiver to 100 slots per year.
- Change the eligibility criteria for the TBI waiver so that individuals in any long term care facility can apply, thus increasing access to the program.
- Further expand access by changing eligibility criteria for the TBI waiver that will allow individuals currently living in the community who need individualized supports and services to avert nursing home placement.

(c) Analysis/Background:

Younger individuals with physical disabilities and those with disabilities related to traumatic brain injury experience very different health and social issues and requirements for community supports than do individuals with developmental disabilities and frail elders. Further these younger people (under 65) represent a much smaller percentage of those needing LTC services.

The Living at Home (LAH) Waiver program, is designed to transition people from more expensive nursing facilities to less costly community settings. The Traumatic Brain Injury (TBI) waiver also provides comprehensive services to individuals with TBI who are re-entering community life. The Model Waiver for children was conceived as a way to provide the customized supports and family nurturing that these children require at home rather than in hospitals and institutions. The program has been a demonstrable success from a programmatic and fiscal standpoint, yet the numbers of available slots has not grown as the population has continued to expand.

Each of these populations is relatively small compared to the larger universe of people requiring long term care services. Their needs are unique and community supports must be customized for individual situations. For example, housing is a primary need for adults and the LAH program has had demonstrable success in locating accessible, affordable housing for participants. Rehabilitation, transportation, attendant care, private duty nursing, educational services, vocational training and employment supports as well as medical day in some instances are other distinct services that these populations must have to be fully included in a community of choice.

These programs offer significant opportunities for consumer and family direction and choice, which has been shown to result in cost efficiencies as consumers become more adept at identifying their own needs and resources.

Community Supports

3.2. Annual COLA in Community Mental Health Rates

Rating: 1.3

(a) Issue:

Community mental health providers continue to grapple with a multitude of problems. Direct service worker salaries are still 10-23% below those of state employees in comparable jobs. Outpatient programs are experiencing unprecedented difficulties in recruiting and retaining clinical staff of all types, primarily because of workload demands in the face of uncompetitive compensation. A critical shortage of psychiatrists

is increasing the time from referral to first appointment and reducing overall access to essential medications and treatment. Training resources are being diverted to other critical needs, jeopardizing quality of care for the most vulnerable adults and children the PMHS serves. As it becomes more and more difficult to staff necessary services in the community, other more expensive and inappropriate settings such as hospital emergency departments, jails and prisons pick up the slack.

(b) Recommendation: The top budget priority for community-based programs that serve the 92,000 children and adults who use Maryland's public mental health system (PMHS) is an annual cost-of-living adjustment (COLA) in reimbursement rates. This is crucial to resolving a worsening workforce crisis. It is required, "subject to the limitations of the state budget," by SB447 enacted during the 2006 General Assembly session. The Community Services Reimbursement Rate Commission, charged in SB447 with recommending the amount of the COLA, has determined that community mental health should receive a 3.71% increase in FY08.

(c) Analysis/Background:

The legislature and the outgoing Governor included a 4% COLA for community mental health in the state budget for FY07. *This was first such increase in more than a decade.* In addition to helping community providers cope with the higher costs of energy, employee health insurance, and other essentials – which go up as much for these service programs each year as they do for every other health care provider and every other business -- the COLA is allowing providers to give much-needed pay raises, fill staff vacancies, and work in partnership with the Mental Hygiene Administration (MHA) to begin putting fiscal incentives in place to improve quality and expand the use of evidence-based practices, among other important advances.

It is also enabling community programs to restore vital services that were lost in prior years because of cuts taken to offset budget deficits caused by service demand exceeding budget capacity. Community providers worked closely with MHA, state budget officials and legislators to end the system's deficits in order to preserve the public mental health carve-out that has been so successful in improving consumer access and to give stakeholders breathing room to plan the next generation of managed public mental health care. They made major sacrifices in the process, including laying off or not filling 600 staff positions.

The FY07 rate increase is providing only short-term relief. A long-term solution to this service area's workforce challenges will be achieved only with inflationary adjustments year after year. Reimbursement for community-based services for Marylanders with psychiatric disabilities should take inflation into account every year, just as it does for citizens who use community hospitals, community health centers, nursing homes, managed care organizations and other major public health services – reimbursement parity. (For more information on disparities in health reimbursement, see pages 19-23 of the *DHMH Overview* budget analysis in the 2006 budget document section of the Maryland General Assembly website.)

Community Supports

3.3. Funding of Developmental Disability Services

Rating 1.3

(a) Issue: The Developmental Disabilities Administration (DDA) in DHMH funds community-based supports for 22,000 individuals; the supports and services are provided by over 160 agencies that are predominantly non-profit organizations. Funding for community-based supports, including residential, employment, day habilitation, family supports, and respite, has fallen increasingly short of the actual cost of providing services, as a result of the absence of cost-of-living increases for several years, combined with a growing number of unfunded mandates.

(b) Recommendations: Fund the 3.83% cost-of-living-adjustment (COLA) for developmental disability service providers in FY 08, as mandated in state law.

(c)Analysis/Background: In the 1980s, a major transition occurred in the developmental disabilities field from state institution-based services to community-based services, resulting in better and more cost-effective supports. Research clearly shows that individuals, regardless of their disability, fair far better in integrated community settings than institutions. The cost of a community placement in Maryland (residential and day services) averages \$77,000, as opposed to the average cost of an institutional placement, which averages over \$160,000 annually.

While the state has both a moral responsibility and a vested financial interest in adequately funding community-based services for people with developmental disabilities, Maryland has continued to under-fund community services. Although the state invested \$80 million in a wage initiative to address the poor pay of direct support staff, providers have gone without virtually any cost-of-living increase for over six years, as the cost of housing, utilities, insurance, supplies, and gasoline increased significantly.

The stability and quality of community supports will become increasingly jeopardized unless the state takes action. An important step in stabilizing the funding system occurred in 2006, when the General Assembly passed SB 447, which mandates that funding for a cost-of-living adjustment for developmental disability and mental health providers be included in the budget, based on availability of funds. DDA services, including the COLA, are funded by both state general funds and federal Medicaid dollars.

Issues such as recruitment and retention of qualified staff, choice of services, and capacity to serve people in high-cost areas, hinge on adequate funding of developmental disability services. Implementation of a COLA is crucial. See *Community Supports Attachment 1* in Appendix for more information.

Community Supports

3.4. Developmental Disabilities Community Services Waiting List and Emergencies **Rating: 1.3**

(a) Issue

16,000 children and adults with developmental disabilities and their families are on the Developmental Disabilities Administration (DDA) Community Services Waiting List for family support, employment programs, and community day and residential supports. 41% of the individuals who need community services are at the Crisis levels, as determined by DDA.

In addition, there are unexpected crisis/emergencies that occur throughout the year. These are often people who are not on the Waiting List as when a 90 year-old parent dies, leaving their 50 year-old son alone; or a person on the Waiting List becomes an emergency due to the death or life-threatening illness of their family caregiver. It is not infrequent that a person who started on the Waiting List ten years ago escalates to a crisis/emergency after years of no services.

(b) Recommended Action

- A multi-year Developmental Disabilities Waiting List Initiative is needed, similar to the level of commitment provided by the Administration in 1998 – 2002. Funding in FY 2008 to serve 20% of the people on the DDA Community Services Waiting List is needed for the first year of the initiative.
- \$5 million for 154 anticipated emergency/crisis situations.

(c)Analysis

Maryland is the third wealthiest state in the nation, yet it ranks 44th in funding for individuals with developmental disabilities. Maryland is seen as a progressive leader in many areas in disability policy; yet its total fiscal effort and funding commitment to persons with developmental disabilities is below that of Kentucky, Louisiana, Mississippi, New Jersey, New York, Pennsylvania, Tennessee, and Texas. Maryland

would need to make a long-term commitment to grow its community and family supports system over 10 years (with annual 7% increases) just to catch up with the *average* state.¹

From FY 2003 - FY 2005, there was no new funding for people on the DDA Community Services Waiting List. As a result, the Waiting List has grown from 8,000 to 16,000 children and adults. People from every county are on the waiting list. The FY 2007 budget provided \$10M to serve 1,225 individuals from the Waiting List and \$2.7 million for emergency/crisis services for 154 individuals. A dramatic increase is needed in the DDA budget now as a part of a multi-year strategy to assist individuals and families in critical need of community services.

Community Supports

3.5. Availability of Independent, Comprehensive Care Coordination (Care Management) in any Managed Long Term Care Programs Implemented by the State

Rating: 1.2

(a) Issue: Continuing to make available comprehensive, independent care coordination in long term care is essential in Medicaid programs serving individuals with developmental, physical, and cognitive disabilities, as well as chronic health concerns, mental health issues, and complex medical needs. Independent voluntary care coordination should be made available for individuals within any programs that may proceed from the Deficit Reduction Act and/or the proposed Community Choice Waiver (CCO) program and associated CCO pilot. This care coordination service must be independent of any managed care program that may be designed to serve the population.

(b) Recommendation:

1. Offer independent comprehensive care coordination, independent of managed care organizations, as part of any current or future long term care package. Coordination, or care management, may be provided by historic individual providers, such as those that currently serve individuals with mental health issues or those with physical disabilities. Qualified independent care coordination organizations could be selected to provide such care coordination through a state implemented competitive process.
2. Maintain the access to care, quality of care, and consumer protections enacted under SB 819 for any pending or future long-term care managed care program in Medicaid.

(c) Analysis/Background:

The multiplicity of programs serving people with disabilities and specialized health concerns, established through diverse and sometimes competing authorities, results in fragmentation, overlap and waste. In this environment, comprehensive, independent care coordination will serve to:

- Eliminate the innate conflict that arises when care coordinators are the employees of a managed care organization and must be sensitive to the interests of the company.
- Put the consumer at the center of planning and decision making; consumer direction supports appropriate and cost efficient service provision.
- Coalesce the various potential sources of funding to appropriately support the individual to achieve desired outcomes for health, safety, community inclusion and independence.
- Work with departments and agencies to find solutions to access and quality issues.
- In concert with consumers, identify needs and priorities for community living situations, which are demonstrably less costly than continued facility placements.
- Provide expert discharge planning, particularly from facilities to less costly community settings; expert discharge planning ultimately reduces or eliminates the number of days that people may have to return to a hospital or facility.
- Establish the necessary relationships with consumers that will lead to reducing errors in obtaining costly durable medical equipment items and home accommodations.

Community Supports

3.6. Bridge Subsidy Program

Rating: 1.3

(a) **Issue:** The Maryland Department of Housing and Community Development implemented a *Bridge Subsidy Demonstration Program* in 2006. The program will provide State-funded short-term rental assistance (up to three years) for 100 individuals with disabilities who are receiving Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), while they await permanent housing assistance. Local public housing authorities (PHAs) administer the program. The program is unique and serves a tremendous unmet need, yet it was designed as a pilot to test its impact. Among its limitations:

- It will serve only 100 people
- It is available in only some jurisdictions in Maryland.

(b) **Recommendation:**

1. Make the *Bridge Subsidy Program* permanent.
2. Expand the program to:
 - a) Serve significantly more people each year. In FY 2008, the program should serve a minimum of 300 people. AND
 - b) Implement the program in all jurisdictions in the state and resolve barriers that preclude the participation of some jurisdictions.
3. Allow non-profit organizations to administer the bridge subsidies when the PHA elects not to do so.
4. Evaluate the program and make improvements necessary to accomplish the program's goals, including statewide availability, streamlined access and long-term viability.

(c) **Analysis/Background:**

Many people are on very long PHA waiting lists for rental assistance (Section 8). The *Bridge Subsidy Program* was designed to address this. The budget is \$2.1M for the three year demonstration. Participants may not have income greater than \$12,000 annually and are required to pay 30% of their adjusted monthly income for rent.

Participating public housing authorities must agree to provide permanent housing assistance to the participant before the expiration of the participant's 3 year term on the *Bridge Subsidy Program*.

A service plan is developed with each eligible participant, which they must commit to. The agencies selecting participants take the lead in helping participants find appropriate housing. Participants must agree to adhere to all program requirements, including maintaining eligibility for permanent housing assistance (so they can transition off of the temporary bridge subsidy), completing rental and financial management training, making timely bill payments, and adhering to all lease requirements.

The program is being implemented as a pilot in Allegany, Caroline, Carroll, Dorchester, Frederick, Garrett, Howard, Harford, Kent, Somerset, St. Mary's, Talbot (excluding City of Easton), Wicomico, Worcester Counties, plus the City of Frederick and the City of Cumberland.

Health

4.1. Re-Design of Medical Assistance Personal Care Program

Rating: 2.1

(a) **Issue:** The Maryland Medical Assistance Personal Care Program (MAPC) does not meet the personal care needs of the majority of people in the program because it is neither well structured nor adequately funded.

(b) Recommendation:

- 1) Sunset the Personal Assistance Services Advisory Committee (PASAC) and reconfigure the committee with strengthened consumer representation and specific mandates, including re-designing the MAPC program to better serve participants.
- 2) The program re-design should create hourly rates of pay tied to the prevailing wage rate for personal care workers in each area of the State and should factor in a transportation allowance, particularly in rural areas.
- 3) The new MAPC program should allow family members to be paid care providers consistent with federal law when it is the consumer's choice.
- 4) A report on the re-designed program and its costs should be presented to the Governor and legislature by December 31, 2007.
- 5) Funding the re-designed program should be a priority in the FY 2009 budget.

(c) Analysis/Background:

The MAPC program was developed in the mid-1980's and modeled after a program in Oklahoma where neighbors were paid \$10 per day to assist people with disabilities. Maryland also structured the MAPC program with a per diem rate and defined levels of service that avoided reference to hours of service provided. The program has long been ill-functioning and in need of overhaul. In fact, one county, i.e., Montgomery, has twice analyzed whether to administer this program and has declined both times due to concerns over its inability to assure a quality program given the limited fiscal resources available in the program.

For individuals who need and want only personal care services, a re-designed and significantly improved MAPC Program has the potential to deliver services in a cost effective manner.

Health**4.2. Restore Medicaid Level of Care Eligibility for People with Cognitive Impairments **Rating: 1.3****

(a) Issue: Individuals with cognitive impairments, such as Alzheimer's disease, traumatic brain injury, and mental illness who are otherwise financially eligible for Medicaid are denied access to Medicaid long-term care (LTC) services, including home and community-based services, due to DHMH's stringent level of care standard for medical eligibility that far exceeds that of the federal government and 34 other states. The federal standard and that of most other states requires that the individual need 24-hour supervision or 24-hour skilled nursing care. Maryland's current policy only allows medical eligibility for individuals who need 24-hour skilled nursing care.

(b) Recommendation: Restore Medicaid medical eligibility for individuals who need either 24-hour supervision or 24-hour skilled nursing care to ensure that individuals with cognitive impairments receive necessary long-term care services, including home and community-based services (HCBS).

(c) Analysis/Background: In 1995 DHMH implemented through departmental policy, a level of care standard for Medicaid medical eligibility that is much more stringent than the standard used by the federal government and 34 other states. The effect of this change in determining level of care was to restrict eligibility for LTC largely to individuals with somatic care needs, rather than those with either cognitive or somatic needs. Individuals with Alzheimer's disease, other dementias, traumatic brain injury, and mental illness, who largely need 24-hour supervision for their safety and health and that of others around them, rather than 24-hour skilled nursing care, are often denied access to any Medicaid LTC services if they do not have a qualifying co-occurring somatic condition. Currently, access to Medicaid home and community-based services in Maryland is likewise restricted to only those individuals who require 24-hour skilled

nursing care, as the state applies the same level of care standard to determine eligibility for nursing facility services and HCBS.

Under the recently passed federal Deficit Reduction Act (DRA), states now have the option, without seeking a federal waiver, to implement a second level of care standard for HCBS that is less restrictive than the standard used to determine the need for 24-hour skilled nursing care. This allows Maryland the opportunity to pursue an incremental approach to restoring Medicaid eligibility to individuals with cognitive impairments who need 24-hour supervision. Coupled with this approach would be the goal of ultimately restoring full medical eligibility for people with cognitive impairments in all LTC settings.

Housing

5.1. Housing Registry

Rating: 1.1

(a) Issue: There is no avenue by which individuals with disabilities can quickly and easily locate up-to-date information about available rental units that are affordable and/or accessible. There is also no place where developers, landlords and building managers can list their rental units that are affordable and/or accessible. As a result, units that are accessible are rented to people who do not need them and units that were subsidized with public funding to make them affordable for people with disabilities are not always occupied by people with disabilities.

(b) Recommendation:

The Department of Housing and Community Development and Department of Disability, in collaboration with stakeholders, should establish and maintain a statewide on-line affordable and accessible housing registry that:

- 1) Includes current information on rental units such as rent levels, accessible features and vacancy status.
- 2) Mandates that developers/building owners that received public funding to build or operate their developments report to the registry. This may require legislation and/or change in regulations and policies related to LIHTC and other DHCD programs.

(c) Analysis/Background:

This is an issue of linking available units with individuals for whom they were intended, and benefits everyone involved. In addition to the benefits to individuals with disabilities, a registry helps building owners/managers decrease their vacancy rates, find people who need their apartments' unique features, and helps them comply with state law. In Maryland, apartment owners/managers are only required to market their units intended for people with disabilities for a limited amount of time; usually 30-60 days. If they do not find a qualified renter with a disability, they can rent to non-disabled individuals.

The state has an *Accessible Housing Registry* from 2005 on the DHCD website but it is incomplete and incorrect. It does not contain information regarding availability of units in any property. The federal Department of Housing and Urban Development has a list of apartment buildings that received federal assistance to make them more affordable. However, the list is also virtually useless because it is never updated.

There has been success in other states from which Maryland can learn. The Mass Access Accessible Housing Registry³ is a free program that helps people with disabilities find rental housing in Massachusetts, primarily accessible and barrier-free housing. The database tracks accessible and affordable apartments throughout the state, maintaining information about their availability. Mass Access distributes current vacancy information to disability agencies and people with disabilities daily. At first, landlords complained that the registry was

³ www.massaccesshousingregistry.org

an onerous burden but now they are pleased to have it because their accessible units are getting rented quickly to people who need them.

Housing

5.2. Utilizing Low Income Housing Tax Credits for the Development of Affordable Housing for Individuals with Disabilities

Rating: 1.2

(a) Issue:

The federal Low Income Housing Tax Credit (LIHTC) program is the largest source of funding for the production of rental housing for individuals and families with low-incomes. The LIHTC program is administered in Maryland through the Department of Housing and Community Development.

The LIHTC program targets households with incomes at or below 50 percent or 60 percent of area median income, with some incentives to reach lower income families. However, many people with disabilities receive Supplemental Security Income (SSI), which is 14% of area median income.⁴ The LIHTC program is not structured to create units that are affordable to extremely low-income households such as people with disabilities receiving SSI or SSDI. LIHTC units are not affordable to SSI/SSDI recipients without rental assistance.

DHCD estimates a shortage of 29,000 units for people with disabilities over the next ten years. More can be done to maximize the impact of low income housing tax credits on the development of affordable housing for individuals with disabilities.

(b) Recommendation:

1. Make improvements in how LIHTCs are awarded to increase the development of units affordable to people with disabilities at SSI/SSDI income levels:
 - Analyze the impact of the rating and ranking criteria used to award LIHTCs on the development of rental units that are affordable for people with disabilities, including SSI/SSDI recipients. The analysis should identify what award criteria are effective and what changes would increase affordability for individuals with disabilities who are extremely low income. Implement improvements identified.
 - Provide an incentive for projects that obtain a commitment of project-based rental assistance (e.g., federal vouchers or HOME funds) from their local public housing authority that would be linked to units for individuals with disabilities.
2. Develop units with rents affordable to people at SSI/SSDI income levels by including long-term rental assistance in the overall financing strategy of LIHTC properties:
 - Use HOME funds to permanently subsidize the rent on units for people with disabilities receiving SSI and/or SSDI in each LIHTC property.
 - Create a state *project-based* appropriation to subsidize the rent on LIHTC units for extremely low-income individuals with disabilities.
 - Analyze the feasibility of committing a portion of the state's Sect 8 Housing Choice voucher funding to *project based* vouchers and linking them with the LIHTC program.
 - Research, adapt and implement financing strategies that other states like Connecticut, Massachusetts and Washington have successfully implemented to reach people with disabilities at lower incomes.

⁴ 2006 statewide median income for an individual = \$53,130/yr (Source: DHCD); 2007 SSI amount for an individuals = \$623/month (source: Social Security Administration)

3. Require projects to annually report to DHCD: 1) the percentage of units set aside for individuals with disabilities that are occupied by people with disabilities and 2) the percentage of accessible units occupied by people requiring an accessible unit.

(c) Analysis/Background:⁵

National and state research and experience verify that low-income people with disabilities are experiencing a housing affordability crisis. It is virtually impossible for people with disabilities receiving Supplemental Security Income (SSI) to obtain affordable and accessible housing in the community unless they receive housing assistance. The following information and data demonstrate the urgency in implementing the Disability Workgroup's housing recommendations:

- There are an estimated 588,000 people with disabilities in Maryland, ages 21-64. DHCD estimates a shortage of 29,000 units for people with disabilities over the next ten years.⁶
- People with disabilities are among the poorest of the poor. Many people with significant disabilities rely on federal Supplemental Security Income (SSI) to cover the cost of their food, clothing **and** shelter. As of January 2007, the SSI amount in Maryland for an individual is \$623/month (\$7,476/year). According to the federal government, housing is considered affordable if it consumes no more than 30% of a household's income. For an SSI recipient this would be \$187/month.
- People with disabilities are completely priced out of today's housing market. A national report, *Priced Out in 2004*, found that a person receiving SSI in Maryland cannot afford to rent a modest one- bedroom apartment without rental assistance. On average, they would have to spend 145.5 % of their monthly SSI benefits on rent, which is impossible. An SSI recipient would have to pay 126.8% of their income for an efficiency. Although these are 2004 figures, this disparity has worsened every year since data was first analyzed in 1998. Among other key findings in *Priced Out*:⁷
 - a. SSI was 13.4% of the median income in Maryland. (~14% in 2007)
 - b. In 2004, there was a 3.5% increase in the SSI rate vs. 11.7% increase in the average rent for a one bed unit in Maryland.
 - c. Of the ten Highest-Cost Local Housing Market Areas for 1-Bedroom Units relative to SSI income, Columbia Maryland ranked first in the nation (Individuals with SSI level income would have to pay 189.9% of their income for a 1-BR unit).
 - d. Strong anecdotal evidence suggests that people with disabilities with incomes below 30% of median do not benefit from federally funded affordable rental housing production and rehabilitation activities in proportion to their need for assistance.
- The National Low Income Housing Coalition's research report, *Out of Reach 2006*, ranks Maryland 45th in the nation in terms of the affordability of housing in the state.⁸ Maryland's "Housing Wage" is \$20.17, which is the hourly wage you would need to earn in order to pay what HUD estimates to be the Fair Market Rent for a home in Maryland, spending no more than 30% of your income on housing costs.
- Without an affordable, accessible place to live, even people with a full complement of support services available to them are unable to move to the most integrated setting in the community. This is a key issue that cuts across all disabilities.
- Housing that is considered "affordable" is typically not affordable to people with disabilities so policies, financing strategies and programs that address affordability typically do not reach most low-income people with disabilities. Current public debate about affordable housing is often focused on "workforce housing." Although this is a critical need, it ignores the need of individuals with disabilities who are among the poorest people in the nation. If Maryland is to continue on its path of best practices regarding supporting individuals with disabilities in the community, affordable housing for this group cannot be

⁵ Key Sources: "Opening Doors" and "Priced Out in 2004" by the Technical Assistance Collaborative: www.tacinc.org

⁶ *Governors' Commission on Housing Policy; Final Report 2004.*

⁷ Source: *Priced Out in 2004*; a housing publication by the Technical Assistance Collaborative, Inc. in Boston and the nationwide Consortium for Citizens with Disabilities Housing Task Force.

⁸ Source: "Out of Reach 2006": www.nlihc.org . This research looks at what a family has to earn to be reasonably assured of quickly finding an affordable rental unit in each state.

ignored. The lack of sustainable housing for SSDI/SSI levels of income in fact condemns these persons to more restrictive settings, including nursing facilities.

Housing

5.3. Creation of a DHCD Staff Position for Disability Policy

Rating 1.2

(a) Issue:

The Maryland Department of Housing and Community Development (DHCD) is producing “affordable” housing every year, however this new housing stock is not affordable to people with extremely low incomes, especially individuals and families living on Supplemental Security Income (SSI) benefits. This issue is complex and requires a multi-faceted approach.

In order to address this severe housing crisis, a high-ranking staff position within DHCD is needed that is dedicated to developing and implementing new strategies that increase affordable housing opportunities for low-income persons with disabilities in Maryland.

(b) Recommended Action:

Create a new DHCD staff position, *Special Assistant to the Secretary for Disability Policy*. The goal would be to expand community-based affordable housing for individuals with disabilities. Responsibilities would include, but not be limited to:

- Ensuring that SSI-level income constituents are addressed when determining best uses of all potential housing resources available for affordable housing development.
- Developing and implementing models that combine multiple funding streams to create housing that is affordable to people with disabilities at SSI level incomes.
- Assessing statewide housing needs for individuals with disabilities and continually incorporating these findings into the Consolidated Plan, Qualified Allocation Plan and other federally legislated requirements.
- Ensuring that the needs of persons with disabilities are addressed when allocating federal housing funding such as HOME, CDBG, and any other funding source(s).
- Working in collaboration with state health and human services agencies to implement interagency strategies to address the housing needs of persons with disabilities.
- Working with public housing authorities, county departments of housing, people with disabilities, advocates and other stakeholders to identify and implement local housing strategies and to leverage local funding.
- Providing political leadership in seeking solutions to the housing issues facing persons with a disability in Maryland’s current and future housing market.
- Researching best practices nationally.

(c) Analysis/Background:

The Maryland Department of Housing and Community Development’s (DHCD) stated function is to work “to ensure available housing at all income levels, and encourage strong neighborhoods and viable communities” (MD Manual). DHCD has created policies, plans, programs and capital infrastructure to address affordable housing for many of Maryland’s citizens, but for the most part, these accomplishments have not expanded opportunities for people with disabilities with the lowest incomes in the State.

DHCD should be recognized for developing a greater commitment to addressing the housing needs of individuals with disabilities. In so doing, programs have been developed and modified to reach some people with disabilities. However, these efforts do not reach people at SSI-level income. With competing priorities vying for DHCD staff time, addressing this critical issue requires a dedicated position.

DHCD has estimated a shortage of approximately 29,000 housing units for persons with a disability over the next ten years in Maryland.

Transportation

Greater Baltimore

6.1. Continuing to Improve Paratransit Services for Individuals with Disabilities **Rating: 1.1**

(a) Issue: The Maryland Transit Administration (MTA) provides paratransit services to approximately 16,000 certified individuals in the Greater Baltimore area. MTA has been the subject of a class action lawsuit alleging poor service that does not comply with the ADA.

The class action lawsuit against the Maryland Department of Transportation (“MDOT”) and MTA alleged violations of the ADA and the Rehabilitation Act, resulting in poor on-time performance, a large number of missed trips and faulty communications that caused riders to miss work, medical appointments, school and wait outside for hours in inclement weather at all times of the day and night. In addition some people did not use the service due to its unreliability and were therefore limited in efforts to be part of our communities. MDOT and MTA began to reform the system, purchase new vehicles and hire more staff. The parties reached a settlement agreement intended to build on these positive changes, using a nationally-known consultant to recommend additional systemic improvements.

(b) Recommendation:

1. Ensure that the RFP for new contracts for MTA paratransit service is issued immediately and do not delay the procurement process.
 - Pursuant to the settlement agreement, an RFP for new contracts is due to be issued.
 - The new RFP has been reviewed by the consultant and the parties to the lawsuit and the state has had the opportunity to consider comments. All involved feel it will produce improvements in service and must be issued as soon as possible.
2. Ensure that the budget for paratransit services reflects a reasonable projection for service.
 - Service demand has increased with improvements in service. MTA has had to request supplemental budgets because its initial budget requests are too low. While capital expenditures have increased dramatically to provide many more vehicles and additional runs, the operations staff controlling the reservations and scheduling has not been adequately increased to meet the increased capacity and demand. The law requires the state to plan to serve 100% paratransit demand.
3. Request a sufficient number of PINs to ensure that the paratransit service is adequately staffed.
 - Staff turnover has been a historic problem with MTA staff.
 - Job retention is much better with regular state employees with benefits (PINs).
 - MTA needs to convert 15 contract positions into PINs with benefits.
 - Improve the MTA hiring process so that staff can be added promptly without long delays that result in capacity constraints and poor service.

(c) Analysis/Background:

Transportation is a fundamental need. People with disabilities need paratransit services to be integrated into the community. Unfortunately, though the service has improved, it still fails to show up for an unacceptable number of trips each day. Though MTA continues to make improvements, the three critical recommendations, listed above, address outstanding areas of concern.

Transportation

Statewide

6.2 Continuing to Improve Transportation Services for Individuals with Disabilities: Rating 1.3

(a) Issue: The State of Maryland lacks a seamless transportation system for the citizens of Maryland with disabilities. Issues to be addressed include: providing for the transportation needs of people with disabilities in an urban environment; rural transportation needs; and, progress with improving paratransit, increasing accessibility on fixed-route service, and for increasing availability of accessible taxis. People with disabilities need increased independence and freedom of choice for transportation to work, play, learn, and worship. Increasing accessible taxi and van service in all jurisdictions throughout Maryland will reduce the burden on paratransit services and expand the time, reduce the duration, and increase destination sites for transportation for people with disabilities. This increase freedom will allow individuals with disabilities and their family and friends to go to evening concerts, church, mosque, and synagogue activities, and recreational and social activities within and across jurisdictions.

(b) Recommendation:

- Increase the number of accessible taxi and vans providing service in all jurisdictions by introducing legislation such as the Montgomery County Code which requires 5% of the entire number of licenses be for lift-equipped vehicles. There needs to be a requirement for taxicab companies to have a certain percentage of lift-equipped vans on the road 24 hours a day, 7 days per week.
- The Department, Jointly with MDOT, should review and develop incentives for the purchasing of taxi/vans and increasing their accessibility. Develop tax incentives and other economic incentives to encourage the development of these businesses. This will be an excellent opportunity for expansion of transportation services, especially for small, minority, and women business enterprise. Consider the linking these services and coordination of these services with paratransit service in the jurisdictions that have paratransit services.
- Meet with the Maryland Secretary of Transportation and human service agencies to discuss how state and federal funding for public transit and human service transportation can be used to more effectively and efficiently serve consumers
- Work with local transit and human service agencies to increase travel training on the fixed route system within 6 to 9 months.
- Work with local transit and human service agencies to provide more efficient specialized transportation services that could reduce demand for paratransit.
- Work with local transit agencies to sensitize all bus drivers to the needs of seniors and passengers with disabilities, as part of the plan to increase use of fixed route.
- Establish transfer hubs for paratransit so that people can cross jurisdictional borders across the State.

(c) Analysis/Background:

Transportation is a fundamental need. People with disabilities need paratransit services and also greater access to taxis and fixed route transportation to be integrated into the community. Unfortunately, the services are not coordinated between counties.

Early Childhood:

7.1 Maryland Infants and Toddler's Program (MITP)

Rating: 1.3

(a) Issue: While the number of children and families eligible for MITP services has risen 57% since 2001, state funding has remained under 10% of the over all program costs, despite the fact that this is a state and federally mandated program of services. Consequently, local governments have to shoulder the burden of

funding. In July 2006, six jurisdictions called upon the state to provide adequate funding (according to the statutory funding formula, Education Article §8-416 of the Annotated Code) to ensure that all eligible children and their families receive the appropriate and necessary services, to which they are entitled (Part C of the Individuals with Disabilities Education Act, Education Article §8-416 of the Annotated Code).

(b)Recommendation: Increase funding for the Maryland Infants and Toddler's Program (MITP).

A one time investment of 6.1 Million dollars will then become only \$200-\$300,000 dollar investment if funded each year.

(c) Analysis/ Background: The MD Infants & Toddlers Program is mandated by the State and Federal Government. Regardless of funding, services must be delivered to any eligible child and their family, as this is a family-centered program. Services are to be delivered by providers from the appropriate agency (Education, Health or Dept. of Social Services), as this is an interagency program. In MD, MSDE is the *lead* agency. In each jurisdiction, there is a lead agency as well. 50% of them are local depts. of education.

Historically, this is a program that is under-funded by state and local dollars. As a result, local governments bear the burden of funding the program. Unlike other programs, there are NO wait lists allowed and children can not be turned away based upon income eligibility or lack of insurance, etc. In 2000, state dollars represented less than 2% of the overall cost (\$400,000 in general funds). In 2002, SB419 (Maryland Infants & Toddlers Act of 2002) established a statutory funding formula that provided state funds based upon the number of children receiving services. However, amendments to the Bill allow the Governor to use his discretion in following the funding formula. During that same year, a deal was struck to include one-time money from the Cigarette restitution fund that provided state funding to \$5.2 million. It remained that amount until last year. After public outcry, a \$610,000 appropriation was included in the 2nd supplemental budget. The current level of funding (\$5.8) represents less than 50% of the funding called for in the statutory funding formula. Most counties/city must supply the majority of funding (although they are not required or mandated to do so). In Baltimore County for example, the County funds 72% over the overall cost. (see attached factsheet for state funding levels).

Currently, \$6 million is needed to bring funding to the current levels called for in the funding formula. This represents a one-time increase to bring the program to level funding. Future funding would be based upon the number of kids and would fluctuate year to year (could go down if the number of kids goes down). Please refer to the attached factsheet for additional figures, increases, etc., as well as the Education Article (COMAR, Education Article §8-416) for a full explanation of the funding formula.

IMMEDIATE COST: \$6 million in FY08

FUTURE COST: varies from year to year, but not expected to exceed \$400,000 (based upon child count trends) in any given year (after one-time increase)

Source: MSDE Census Data, 2005-2006, www.marylandpublicschools.org

Source: MSDE/MITP Over-the-Mark Request FY08⁹

Source: Early Intervention Federal Funding Allocations, FY00-FY06, U.S. Department of Education, <http://www.ed.gov/programs/osepeip/funding.html>

Source: Twenty Years of Making a Difference for Young Children and their Families, IDEA Infant & Toddlers Coordinators Assn. http://www.ideainfanttoddler.org/PartC_Good_News.pdf

Early Childhood:

7.2 Division of Early Childhood Development Strategic Plan

Rating:1.3

(a) Issue: In order for children and young adults to be independent, contributing members of our society, they must receive a rigorous, appropriate education and have the necessary support beyond school to do so. These opportunities must begin at birth and extend into young adult-hood. Early intervention services and

⁹ MD Infants & Toddlers Program FY08 Over-the-Mark Justification Request, July 2006

early childhood learning opportunities are the foundation for school readiness and success during the educational years.

(b) Recommendation: Support implementation of the 2006-2009 Strategic Plan of the Division of Early Childhood Development.

(c) Analysis/ Background:

The DCED strategic plan endorses recommendations and strategies from the 2006 Implementation Plan for Inclusive Child and School Age Care (the Plan). The Plan was developed based upon a 2005 statewide Task Force (Governors Task Force on Inclusive Child and After School Care for Children with Disabilities and Special Health Care Needs) that examined the barriers to including kids with disabilities and special health care needs in after school programs and child care programs (center-based and home). The Plan includes increased training opportunities for child and after-school care providers, licensing enhancements to ensure providers are aware of ADA requirements and other oversight requirements. It's important to note, the plan does not currently include the development of a statewide mediation process available to parents and providers that experience discrimination – this is an ongoing problem.

Source: The Division of Early Childhood Development (DECD) 3 year strategic plan (2006-2009), <http://www.marylandpublicschools.org/NR/rdonlyres/AC452A0A-959A-463B-A3A1-81F6C5060041/11472/strategicplan.pdf>

Source: Quality Child Care Equals Better Education (January 2007), National Institute for Early Education Research, <http://nieer.org/news/index.php?NewsID=1399>

Source: Implementation Plan for Inclusive Child and School-Age Care (Report to the Governor and the General Assembly as Required by HB 932)¹⁰

Early Childhood:

7.4 Home & Community Based Autism Waiver

Rating: 1.2

(a) Issue: The Autism Waiver serves 900 students in need of intensive wrap-around services in order to remain in their home and community settings. MSDE, in collaboration with DHMH administers the Autism Waiver. Without these services, many students receiving these services would be placed in residential or out-of-state settings and facilities.

(b) Recommendation: Continue to support MSDE's efforts to improve early identification and services for young children with disabilities by providing funding to increase the number of available slots for the Home and Community-based Autism Waiver

(c) Analysis/ Background: In Maryland, the incidence of Autism has increased by more than 650% since 1995. There are currently more than 1,800 children on the Autism Waiver registry (waiting list). In addition, the state is currently engaged in a Demonstration Pilot to improve screening practices and improve early identification of Autism Spectrum Disorders among Maryland pediatricians. Through these advancements in early identification, it is likely that the need for these critical services will increase.

Source: MSDE Census Data, 2005-2006;

Source: Autism Task Force Report (January 2005), MSDE

<http://www.marylandpublicschools.org/nr/rdonlyres/5f4f5041-02ee-4f3a-b495-5e4b3c850d3e/4934/autismtaskforcememoandreport.pdf>

¹⁰ Implementation Plan for Inclusive Child and School-Age Care, Report to the Governor and the General Assembly as Required by HB 932

Source: ZERO TO THREE, is a national non-profit organization developed to share new knowledge on how children develop in the early years, <http://www.zerotothree.org>

Source: Learn the Signs. Act Early. Funded in part by Autism Speaks, the Autism Society of America, Cure Autism Now (CAN), First Signs, the Organization for Autism Research (OAR) and the American Academy of Pediatrics. (www.cdc.gov/actearly).

PRE-K – 21 EDUCATION

8.1 Universal Pre-K Services

Rating: 1.1

(a) Issue: Sadly, too many children enter school unprepared due to the lack of quality pre-K programs in the United States. One third of children entering kindergarten cannot recognize the letters of the alphabet and more than half do not know basic math concepts. (PEW Charitable Trust). In Maryland, only 37% of students with IEPs enter school fully ready (all domains), as opposed to their counterparts in FARMS and Limited English Proficiency (2005-2006 School Readiness Report, MSDE).

(b) Recommendation: Ensure that forthcoming recommendations from the Universal Pre-K Task Force include equal opportunities and access for children with disabilities and special health care needs.

(c) Analysis/ Background: While the task force includes a representative from the special education community, it is unclear at this time how the needs of children with disabilities and special health care needs are currently being addressed on this task force.

Current state regulations require that all “at-risk” children have available to them the opportunity to participate in pre-K learning in the public school system. “At-risk” is defined as students who meet low-income criteria (FARMS: Free and Reduced Meals program) and expressly excludes children who only meet the definition of having a disability. Some school systems have expanded their local definitions to include children with disabilities, but this is less than ¼ of the school systems.

There is currently a statewide Task Force (Task Force on Universal Preschool Education) as the result of HB 1466 that is charged with studying and making recommendations regarding Universal Pre-K opportunities in Maryland. These recommendations (due to the Governor and General Assembly in December 2007) should be carefully studied and evaluated. Any recommendations must include equal opportunities and access for children with disabilities and special health care needs so all children have access to the same enriched learning opportunities and can enter school ready for success.

Source: School Readiness Data, MSDE (2005-2006), http://www.marylandpublicschools.org/MSDE/newsroom/publications/school_readiness.htm

Source: Advancing Quality Pre-K for All, PEW Charitable Trust http://www.pewtrusts.com/pdf/PreKBrochure_0107.pdf

Source: Pre[K]Now, Better Outcomes for All: Promoting Partnerships between Head Start and State Pre-K (in collaboration with CLASP, Center for Law and Social Policy), <http://www.preknow.org/>

Source: The State of Preschool (amended Nov. 2006), National Institute for Early Education Research, <http://nieer.org/yearbook/>

Source: Closing the Achievement Gap through PK-3 (July 2006), Foundation for Child Development, <http://www.fcd-us.org/PK3ResearchandProfiles.html>

Source: Governors’ Pre-K Proposal, Kids Can’t Wait to Learn, The Trust for Early Education, <http://www.trustforearlyed.org/reports.aspx>

PRE-K – 21 EDUCATION

8.2 Individual Educational Plan (IEP)

Rating: 1.1

(a) Issue: Too often, students and parents are given important information and assessments during an IEP meeting and then asked during the meeting to review and provide thoughtful, meaningful feedback, without having sufficient time to review and consider all information presented.

(b)Recommendation: MSDE should establish regulations that require each local school system provide certain information to parents at least three working days before an IEP meeting:

- *Written results of any assessments/evaluations to be discussed in the coming meeting*
- *Any draft goals and objectives, updates regarding “Present Level of Performance” and service provision plans prepared by school personnel to be discussed at the meeting.*

(c) Analysis/Background: As equal participants in the IEP team process, students and parents should be given the same opportunity to review certain materials and information in advance of the actual team meeting, as is the case with school system personnel and related service providers, among others. Often times the information being supplied, requires careful review and analysis, something that can not occur on the same date or at times, within the same hour to receiving the information and materials.

PRE-K – 21 EDUCATION

8.3. Non-Public, Non-Profit or Private Special Education Training Contracts

Rating: 1.3

(a) Issue: Nationwide, public school systems frequently lack the expertise and capacity to meet its responsibilities under the IDEA (Individuals with Disabilities Education Act) to provide a free appropriate public education to all students. However, Maryland has many organizations, including non-public schools, non-profit organizations, and private institutions which would be capable of serving as a resource for Maryland’s public school systems. Maryland is currently in a second year of special conditions imposed by the U.S. Department of Education (OSEP Division – Office of Special Education Programs) and is in jeopardy of losing federal funding without coming into compliance with certain IDEA requirements. OSEP found that Maryland continues to be in non-compliance with federal IDEA requirements in two areas: 1) least restrictive environment decision-making; 2) provision of related services.

(b) Recommendation: The Governor should include funding in the education budget that is dedicated to building the capacity within the local public school system to meet the individualized needs of students with disabilities. This should be accomplished by formulating a Request for Proposals (RFP) for non-public, non-profit or private special education training contracts that would include co-teaching, observations, and specialized skill development.

(c)Analysis/Background: Funding must include incentives for local school systems and partnerships must be sustained over a minimal period of time to ensure adequate professional training for local school system personnel. These opportunities are especially needed in rural/urban jurisdictions where many students endure lengthy commutes in order to access an education that meets their individualized needs. This, along with other ongoing systemic concerns led MSDE to develop and least restrictive environment workgroup report to address long standing barriers to improving opportunities for children in the least restrictive environment.

Currently, local school systems do not have the expertise, capacity and often times, willingness to include children in general education classrooms or lesser restrictive environments in large part, due to the lack of teacher preparation, teacher training (professional development) or a belief that all children have the right to learn alongside their typical peers. In addition, teachers and staff are unfamiliar with the law, including requirements that IEP teams MUST consider supplementary aides and supports to allow children to participate to the greatest extent appropriate in the least restrictive environment. Too often IEP teams make

decisions about students' placements based upon availability of resources (or lack thereof) rather than based upon the individual needs of a student.

Alternately, non-public, non-profits, and private schools have an abundance of experts at their disposal and teachers experienced in teaching (along with differentiating curriculum) students with disabilities. This expertise should be shared with local school system to assist in building capacity within the local public school system so students are more likely to have opportunities will have an opportunity to attend school in their communities with their age appropriate peers. Not only will this lead to great opportunities to access the general ed. curriculum (called for in both IDEA and NCLB), but will model appropriate behaviors and other indicators and will allow typically developing peers to support and accept a diverse student population.

A Pilot Project for this program is already in place. There are several school systems (Anne Arundel, Montgomery & Baltimore City) that have contracted with non public schools to bring non public teachers into classrooms and model teaching practices for general educators. Simultaneously, they provide instruction while the school system works to build capacity buy improving practices (policies), delivery of professional development and identification of funds to support students once the contractual staff members leave the school system. Hannah More, Kennedy Krieger School, and MCIE are just some examples of organizations either non-public or non-profit organizations which have been working with local school systems over the years on inclusive education.

PRE-K – 21 EDUCATION

8.4. Teacher Preparation

Rating: 1.2

(a) Issues: Given the ever increasing demands of our teachers and the requirements of No Child Left Behind (NCLB), it is becoming increasingly difficult to teach students with a variety of learning style and educational needs. This is especially true for new or inexperienced teachers entering the classroom. Teachers are leaving college ill prepared to teach children with disabilities in the general education classroom. College students are currently only required to take a compliance/IDEA course. Too many enter the working world (classroom) not having knowledge about how to differentiate instruction, understanding behavioral needs, knowledge of supports and services available (through IDEA) for students with disabilities.

(b)Recommendation: Require implementation of the recommendations from the 2006 MSDE's K-16 Workgroup's Ad Hoc Committee on Special Education Teacher Preparation report.

(c)Analysis/Background: The report, developed under the Pre-K–16 Maryland Partnership for Teaching and Learning (is an alliance of the Maryland State Department of Education, the Maryland Higher Education Commission, and the University System of Maryland) includes recommendations and strategies to enhance the preparation of *special* educators to meet federal “highly qualified teacher” requirements, and to “address the preparation for *general* educators who collaborate with special educators and provide access to curriculum and instruction for students with disabilities in general education classrooms.”

Sources: AdHoc Committee on Special Education Teacher Preparation, PreK-16 Partnership for Teaching & Learning, http://mdk16.usmd.edu/images/files/Minutes_-_WG_-_Nov._14_2006.pdf

PRE-K – 21 EDUCATION

8.5. Language Development Resources for Deaf Children

Rating: 1.2

(a) Issues: Many deaf children with hearing parents fail to develop an effective language by the time they enter school. Parents are often not provided with the information and guidance to make appropriate decisions about their child's unique communication needs.

(b)Recommendation: Maryland State Department of Education (MSDE) in collaboration with local school systems should increase the availability of resources to meet the needs of children, including deaf children, in need of language development and reading programs, prior to entering school.

(c)Analysis/Background: Approximately 90% of deaf children are born to hearing parents. Many children, who are deaf, unlike most children who hear, enter the educational system without a competent language base. Consequently, when a deaf child of hearing parents enters public elementary school, that child is typically already well behind children with normal hearing in such critical areas as linguistic proficiency in either spoken English or in sign language. In addition, there are delays in critical thinking skills and problems with social and emotional development because of the central role that language plays in these essential areas. The local education agency should be encouraging parents to meet with educators from the Maryland School for the Deaf and to include this as a viable option. (Gallaudet Research Institute, 1994)¹¹.

PRE-K – 21 EDUCATION

8.6. Standards for ASL Interpreters in the Public Schools

Rating: 1.1

(a) Issues: At present, there are no minimum standards for interpreters working in the public school system.

(b)Recommendation: MSDE should establish regulations requiring that educational interpreters meet certain qualifications and maintain certain standards in order to work in the public school system.

(c)Analysis/Background: The interpreter is the sole source of information that will determine if the child succeeds or fails. The teacher and parents have no way to gauge if the child is having problems with the school work or if the interpreter is not conveying the information appropriately (Patrie, 1993;Stedt, 1992). MSDE has already created a voluntary evaluation system for educational interpreters. Legislation may need to be passed to strengthen the MQAS and require satisfactory proficiency on this assessment as a condition of employment. This effort is compatible with the No Child Left Behind emphasis on highly qualified personnel.

Best Practice: Northern Virginia has established a comprehensive quality assurance system. All of their educational interpreters must go through the quality assurance screening. For interpreters who do well, they are placed on the highest “tier”. Those individuals will get the higher, per hour, salary. The other individuals are placed in tier 2 or tier 3. The salaries are commensurate with their skill level. This allowed for interpreters to improve their skill and move up the tier.

Patrie, C.J. (1993). A confluence of diverse relationships: Interpreter education and educational interpreting. Paper presented at the Convention of the Registry of Interpreters for the Deaf, Evansville, Indiana

Stedt, J.D. (1992). Issues of educational interpreting. In T. Kluwin, D. Moores, & M. Gaustad (Eds.) *Toward Effective Public Programs for Deaf Students* (pp. 83-99). New York: Teacher’s College Press.

Employment

9.1. Assistive Technology for the Deaf

Rating: 1.1

(a) Issues: Rehabilitation Counselors for the Deaf do not have access to technology that will help them successfully place deaf individuals into the workforce; and allow them access to supervisors or other individuals who understand the unique challenges in working with this traditionally underserved population.

¹¹ A Joint Publication by the Conference of Educational Administrators Serving the Deaf and Gallaudet Research Institute (1994). *Implications and Complications for Deaf Students of the Full Inclusion Movement*.

(b)Recommendation: DORS should encourage businesses to utilize existing and emerging technologies (e.g. video conferencing equipment) in an effort to increase the likelihood that young adults with disabilities, including deaf individuals will be successfully placed in meaningful jobs.

(c)Analysis/Background: Many members of the deaf community and other disability populations are making greater use of technologies to effectively communicate. It is imperative that emerging technologies are not only available, but become common-place to businesses and rehabilitation staff as well. With this new technology, not only can Rehabilitation Counselors for the Deaf communicate with potential employers for their consumers; but it offers businesses an avenue of communication which will reduce of cost of ongoing interpreter services.

This new technology also allows the Rehabilitation Counselor for the Deaf access to supervision and support from individuals who understand the unique challenges in working with this population

Employment

9.2. Data Collection System for Community Based Employment

Rating: 2.2

(a) Issue: Currently, neither MSDE, DORS, or the DDA collects systematic data on the outcomes of transition services and other employment outcomes. There is no uniformity among service providers in the kind of employment data collected.

(b) Recommendation: Governor should identify and establish a data collection system that includes consumer satisfaction to measure community-based, employment outcomes for people with developmental disabilities.

(c)Analysis/Background: Consumer surveys of parents of transition aged youth should be carried out to determine the nature and effectiveness of transition planning. Research should be conducted on other ways to collect and measure post-graduation consumer satisfaction of both employers and employees to determine future best practices. (Sources: DDA, June 2006; Employment Systems Transformation Steering Committee, 2006).

Employment

9.3 Employment & Post Secondary Opportunities

Rating: 1.1

(a) Issue: According to the 2005 Disability Status Report (Rehabilitation Research and Training Center on Disability Demographics and Statistics), 58% of the 352,000 Marylanders with a reported disability, ages 18 to 64, are either unemployed or not considered to be in the labor force. Many have the abilities and the desire to be employed, but lack the opportunities and supports, as well as on-the-job experience to do so. While there are efforts underway to improve the delivery of employment and transition services to youth and adults with disabilities, they are few and do not have the appropriate funding to ensure successful systemic outcomes, in large part due to the inconsistency from jurisdiction to jurisdiction and lack of information sharing by agencies and departments to the consumer and their families.

(b) Recommendation:

1. **Full funding of the Transitioning Youth Initiative.** The Transitioning Youth Initiative (TYI) is a program offered through the state's Developmental Disabilities Administration (DDA). It is designed to support young adults with significant developmental disabilities exiting high school at age 21 whom require post-secondary day and employment services to maintain skills and assist with their integration into the workforce.

2. **Support recommendations from the Employment System Transformation Steering Committee**, including the need for additional funding to build capacity within the Department of Rehabilitative Services (DORS) aimed at increasing the capacity to serve additional and existing students and improve delivery of services to those current receiving evaluation and employment services. The recommendations of the ESTSC report focused on effecting change to align statewide resources to achieve the goals of person-centered employment planning, improving statewide visibility of the potential benefits of employing persons with disabilities, increasing access to and effectiveness of one-stop centers, increasing assistance to employers, simplifying referral and eligibility procedures, expanding work-based experience as part of the transition process for youth, increasing the availability of long term employment supports and exploring options to increase the quality and availability of job coaching.

(c) Analysis/Background: A sizable share of the state budget is devoted to educating students with disabilities. This investment is well spent when individuals with disabilities are gainfully employed and giving back to the system, but in order to do so, they must be provided with the same opportunities as their typical peers and the necessary supports to ensure success.

Source: DDA, June 2006

Source: Employment Systems Transformation Steering Committee Recommendations, 2006

Source: Postsecondary Education Options for Students with Intellectual Disabilities, TransCEN, Inc.,

http://www.communityinclusion.org/article.php?article_id=178&type=topic&id=7

Source: National Center of Secondary Education & Transition (NCSET), Information & Practice Briefs, January 2007, <http://www.ncset.org/publications/NCSETcatalog.pdf>

Source: Students with Disabilities Preparing for Post Secondary Education, U.S. Department of Education, <http://www.ed.gov/about/offices/list/ocr/transition.html>

Source: ED454674 - Postsecondary Education and Employment for Students with Disabilities: Focus Group Discussions: Supports & Barriers in Lifelong Learning, Education Resources Information Center, http://eric.ed.gov/ERICWebPortal/Home.portal?_nfpb=true&_pageLabel=RecordDetails&ERICExtSearch_SearchValue_0=ED454674&ERICExtSearch_SearchType_0=eric_accno&objectId=0900000b8014122c

Employment

9.4. DORS Evaluation

Rating: 1.1

(a) Issue: The Department of Rehabilitation Services (DORS) is the lead agency in supporting employment related services for persons with disabilities. However, DORS has been chronically under-funded and understaffed for the responsibilities it has. Additionally, DORS is being monitored by the Federal government.

(b) Recommendation: The Governor should direct that there be a comprehensive review and evaluation of the performance, staffing and funding of DORS with the aim of improving its performance and cost effectiveness.

(c) Analysis/Background: DORS is a secondary or tertiary function within the MSDE, but plays a vital role in supporting its efforts of disabled persons to be productive, self-supporting citizens. DORS has not been adequately funded or staffed to meet the heavy demands on its resources. The recommended study would evaluate DORS performance, recommend optimum funding and staffing, improve operations and improve accountability of this agency.

Department of Disabilities

10.1. Mission of the Maryland Department of Disabilities

Rating: 2.3

(a) Issue: When it was created in 2004, the MDOD was charged with unifying State policy regarding persons with disabilities. The Department's overall goal is to secure the civil rights of all Marylanders with disabilities through collaboration with all State government agencies. The MDOD legislation did not communicate any intent for the Department to provide services.

(b) Recommendation: Maryland Department of Disabilities (MDOD) should serve as the disability policy advocacy organization, the disability community desires by identifying the key policy issues that are cross-cutting throughout the State and county governments that impact people with physical, developmental, sensory, psychiatric and cognitive disabilities, and provide coordination of these key issues. We recommend that this office not be a service provider. Our recommendations include:

- Developing a plan for soliciting and incorporating the feedback of State and local boards, State departments, and constituent groups in the formulation of disability policy for the State of Maryland; and
- Expanding the scope of the emergency preparedness policy areas to include public safety in general; and
- Add or convert positions/policy areas for:
 1. Armed services/veteran's affairs for coordination of entitlements,
 2. Assistant Attorney General/legal affairs,
 3. State Americans with Disabilities Act Coordinator,
 4. Budget /contracts Manager,

(c) Analysis/Background:

There are three main areas that would push this Department ahead on becoming the policy and advocacy component of government that is needed. These areas are increased communication with the larger disability community; a redesigned focus on public safety and some additional staff positions.

First responders are responsible for ensuring the safety and security of all Marylanders, including persons with disabilities across Maryland. Everyday, not only in large-scale emergency situations, Maryland first responders encounter persons with disabilities. These individuals deserve the most appropriate service delivery to address their needs. Recognizing and responding to persons with disabilities requires that first responders participate in specialized training and employ specialized tactical strategies to affect both public and officer safety. Moreover, a 2003 federal court ruling held that police agencies and other government organizations can be held liable for not training their personnel to serve those with disabilities appropriately.

The War in Iraq and Afghanistan, coupled with the Realigned Base Closing, has resulted in more armed services personnel relocation to the Maryland Area. Both Wars have resulted in more armed and civilian personnel returning to the area with disabilities as a result of wounds and injuries suffered in the Wars.

Veteran Services, while responsive, are not knowledgeable about the wide range of community based disability and advocate services available in the State. There is a need for an Assistant Attorney General or a staff attorney to assist with revision regulations, review and development of laws, and contracts that affect people with disabilities.

A statewide Americans with Disabilities Act (ADA) coordinator is needed to train State agency ADA coordinators, and to ensure ADA compliance and linkages across local jurisdictions. A qualified accountant with budgetary experience is needed to develop and review the Department's budget and those of other State agencies whose budgetary items affect disability services. Budgetary assistance may also be required for review of any RFPs and grants that may come under the Department's purview.

Department of Disabilities

10.2. Advisory Council to the Office of Deaf and Hard of Hearing

Rating: 1.1

(a) Issue: In order to successfully guide the Office, the function of the Advisory Council needs to evolve from an advisory board into a governing board. In addition, the structure of the Board needs to be reviewed and modified. For the Board to assist the Governor effectively, its members must have knowledge of deafness/deaf culture as well as issues confronting all individuals with hearing loss. This will allow for the broad issues affecting deaf, deafblind, hard of hearing, and late-deafened individuals to be prioritized and addressed.

(b) Recommendation: The ODHH, in partnership with the ODHH Advisory Council, should establish procedures for the accountability of the Office of Deaf and Hard of Hearing (ODHH) leadership to the Governor, ODHH Advisory Council, and the deaf and hard of hearing community, including restructuring the Advisory Council as a governance council.

(c) Analysis/Background:

To establish greater accountability to the Governor and the public, more effective working relationships among ODHH and other State agencies are needed. To address the unique communication barriers and needs of deaf and hard of hearing individuals, ODHH must work closely with the Maryland Department of Disabilities (MDOD) and other State agencies to promote better access and appropriate services for this population. This recommendation specifically addresses the intent of the Governor and Legislature in establishing ODHH as a “coordinating office of the Governor.” It includes working with

- State agencies to provide universal captioning and assistive listening systems;
- Maryland Department of Transportation to ensure accessibility of driver’s education classes;
- Maryland State Department of Education to improve transition planning, upgrade the academic achievement of deaf students, and establish an ongoing mechanism to ensure that educational interpreters are qualified;
- Department of Health and Mental Hygiene to create accessible mental health services and improve services to deaf individuals funded through the Developmental Disabilities Administration;
- Division of Rehabilitative Services to promote better rehabilitation services and more employment opportunities;
- Office on Aging to ensure accessible nursing homes and services;
- Maryland Accessible Telecommunication and Maryland Relay to publicize the Equipment Distribution Program; and
- Office of Minority Affairs to promote business ownership and state procurement for disabled business owners.

ODHH needs to work with the proposed State ADA coordinator to ensure that all State programs and services include the needs of the deaf and hard of hearing population so that they do not inadvertently violate the Rehabilitation Act and ADA. Finally, greater coordination of ODHH programs and services would increase accessibility and provide better services while reducing State liability.

Department of Disabilities

10.3. Maryland Department of Disabilities Physical Accessibility

Rating: 1.2

(a) Issue: There are accessibility challenges with the current location of the MDOD Office, including physical and communication barriers. It is imperative that all individuals with disabilities find it relatively easy to visit and communicate with MDOD.

(b) Recommendation: We recommend greater access to State agencies and their resources for all Marylanders. The MDOD office space should serve as the model for universal accessibility and design. First MDOD’s office space should be evaluated to determine if it is as accessible to the public as it should be, and large enough to house MDOD, ODHH and the DD Council. Then, the level of accessibility should be

reviewed and modified accordingly, so that persons with disabilities have more access to the office and its resources. We also recommend a review of all State offices for accessibility, Americans with Disabilities Act (ADA) compliance, and a plan to serve persons with Limited English Proficiency (LEP).

(c) Analysis/Background:

There are accessibility challenges with the current location of the MDOD Office, including physical and communication barriers. It is imperative that all individuals with disabilities find it relatively easy to visit and communicate with MDOD. Currently there are few materials printed in languages other than English, this is a major problem to the diverse cultures in the state, all of which are affected by disabilities. The technology to be used by individuals who are hard of hearing when visiting the office is not adequate.

Department of Disabilities

10.4. Local Disability Liaisons

Rating: 1.1

(a) Issue: There is a strong need for communication between the MDOD and local entities serving people with disabilities.

(b) Recommendation: The MDOD should work with local districts to establish local disability liaisons, and incorporate into someone's job description, in each Maryland jurisdiction to strengthen community-based (vs. regionally-based) services. These liaisons, to be located within health and human service organizations, would provide State and county referrals, and coordinate State and county-funded disability program service delivery. The subcommittee finds that the dissemination of State-directed information and related services at the local level is key to effective service delivery. One of existing

(c) Analysis/Background:

There is a strong need for communication between the MDOD and local entities serving people with disabilities. Since individuals generally go to their local jurisdiction to obtain disability-related supports, all jurisdictions must maintain the same information on available resources, programs, and services. The establishment of local liaisons would provide Marylanders with disabilities and their families better access to the supports they need for independence in their communities. It would be up to the MDOD to determine if these would be new, fulltime positions or could be worked into current employees' job descriptions.

Department of Disabilities

10.5. State-Wide Disability Specific Task Forces

Rating 1.1

(a) Issue: Many jurisdictions in the United States becoming innovative leaders in policy and practice on different disability specific issues because they have coordinated taskforces that bring advocates, service providers and agencies together.

(b) Recommendation: The MDOD should introduce legislation to create Statewide task forces regarding urgent populations and issues. Based on information reported to this committee, we recommend that task forces be introduced on the following issues:

- Autism; and
- Individuals with Forensic Issues Court-Ordered to the Developmental Disabilities Administration; and
- Services for People with Traumatic Brain Injuries that occur after Age 22.

(c) Analysis/Background: In the process of becoming the most progressive, customer-focused State government, Maryland State agencies, lead by MDOD, must identify and promote best practices; advocate and coordinate collaborative work; and ensure that relevant experts from around the State pool their collective resources to address the public policy implications of pressing disability-related issues.

Charging task forces to develop recommendations and related accountability measures on urgent issues for presentation to the Governor and General Assembly would allow experts from across the State to align and set direction for improvements.

For example, many other states, including California, Illinois, Indiana, Florida, Maine, New Hampshire, Ohio, Oregon, Pennsylvania, Texas, Washington State, and Wisconsin, have instituted autism task forces to identify the nature of the problem as it exists today, and to forecast the resources needed to address autism in their states now, and in the future. As California's Assembly Speaker Fabian Nunez stated, "Autism is the fastest growing developmental disability in the U.S ... We need to understand the policy implications of this growth and how the state should best prepare." The State of Maryland has neither assessed the comprehensive needs of Maryland families facing autism over the lifespan, nor created a plan or vision for providing services to this growing population in the future. To be responsive to the needs of all Marylanders, including Maryland taxpayers, MDOD should begin drafting task force legislation immediately.

Department of Disabilities

10.6. Merit Based Employment at the Department of Disabilities

Rating: 2.1

(a) Issue: Most of the staff of the Department of Disabilities are at-will/appointed positions.

(b) Recommendation: MDOD should review all staff positions and, where appropriate, convert at-will appointments to civil service positions to maintain a more stable workforce, promote continuity and an institutional history, and provide civil service protection to its employees.

(c) Analysis/Background:

The most important attribute for a new organization is credibility. Credibility includes permanency, management support and confidence of associated staff outside of the organization. MDOD came into existence with most staff being appointed rather than placed in merit status.

The Secretary and her Chief of Staff serve as political appointees, and this is in the enabling legislation. Some professional staff are former staff of the Governor's Office on Individuals with Disabilities, some new appointees and others were transferred from other government offices. There are 24 appointees and 4 merit staff. To promote some continuity and institutional history, we recommend where appropriate conversion of more positions to merit status.

Department of Disabilities

10.7 Commission on Disability

Rating: 1.1

(a) Issue: In the interviews with staff and personnel of MDOD, it became apparent that the Maryland Commission on Disability could play a greater role across the State if all the Commission's members were actively involved. The commission could also become a venue for communication between jurisdictions.

(b) Recommendation: The MDOD should restructure the Maryland Commission on Disability to include at least one designee of local commissions on disabilities. The Commission needs more representation from across the State, and to be more in coordination with local jurisdictions, where services are delivered in "the community." In order to make this happen we recommend adding 4 members who are active and in good standing members of local commissions on disability. The Statue for the Maryland Commission on Disabilities should be revised to require meeting 6 times per year, instead of twice a year.

(c) Analysis/Background:

The entire Commission needs to be an involved and committed group of people. For the Commission to serve as the advisory arm of the MDOD, members need to be in constant communication with the part of the disability community they represent. Regular communication among the Maryland Commission on Disability and the local commissions would also improve the ability of commissioners to advise MDOD on current issues.

Governor O'Malley's Disabilities Transition Team

Co-Chairs of Transition Team:

Stephen Sfekas, Attorney at Law
Joel David Myerberg, Chairperson Emeritus, Independent Living Foundation &
Chairperson Emeritus, Maryland Disabilities Forum

Department of Disabilities Subcommittee

Co-Chairs:

Lisa Gibson, Board of Directors, Autism-ASP Association of Calvert County
Betsy Luecking, Montgomery County Government

Members:

Eugene Sadick Community Advocate
Kelby Brick, Attorney at Law
Milagres V. McGuire, Disabilities Professor/ Hispanic Democrats of Montgomery Co.
Nollie P. Wood, Jr., Mayor's Commission on Disabilities
Sarah Basehart, The Arc of Maryland
Laurie Yaffee, University of Maryland, Deaf Services
Judy C. Stout, Deaf and Hard of Hearing Patient Activist
Nadim Khan, Chief Operating Officer, Jewish Foundation for Group Homes
Jane Brooks, Advocate

Olmstead/Institutions Subcommittee

Co-Chairs:

Bea Rodgers, Resource Connections of Prince George's County
Virginia Knowlton, Maryland Disability Law Center

Members:

Cristy Marchand, The Arc of Maryland
Bob Williams, Citizen/former Commissioner, Administration on Developmental
Disabilities, U.S. DHHS
John Sorensen, Cross Disability Rights Coalition
Ken Capone, Cross Disability Rights Coalition
Mark E. Engberg, Maryland Coalition of Advocates for the Retarded
Emily Hoffman, On My Own
Laura Cain, Maryland Disability Law Center
Sharon Krevor Weisbaum, Brown, Goldstein & Levy LLP
Steve Eidelman
Tony Records, TRA, Inc.
Lori Doyle, Community Behavioral Health Association of Maryland
Jim Rosner, Arc-MD Legal Advocacy

Transportation/Community Supports/ Health/Housing Subcommittee

Co-Chairs:

Brian Cox, Maryland Developmental Disabilities Council
Laura Howell, Maryland Disability Law Center

Members:

Nadim Khan, Chief Operating Officer, Jewish Foundation for Group Homes
Brian Cox, Maryland Developmental Disabilities Council
Cathy Raggio, Executive Director, Independence Now
Karen-Ann Lichtenstein, The Coordinating Center
Lorraine Sheehan, Maryland Disabilities Law Center
Laura Howell, Maryland Association of Community Services
Michele Douglas, Alzheimer's Association/ Maryland Senior Citizens Action Network

Education and Employment Subcommittee

Chair:

Kelli Nelson, Advocate

Members:

Lisa Gibson, Board of Directors, Autism-ASP Assc. of Calvert Co.

Judy C. Stout, Deaf and Hard of Hearing Patient Activist

Careen Wallace, Member of the Board, Autism-Asperger Association of Calvert County

Dr. Mary Ellen Lewis, Kennedy Krieger Institute

Dorie Flynn, Advocate-MANSEF

Michele Hart, Board member for the Arc of Baltimore and KKI's Citizen Advisory Committee (UCEDD), Developmental Disabilities Council-Public Policy

Simone Martinez, Parent in Howard Co./Substitute teacher